DEPARTMENT of HEALTH and HUMAN SERVICES

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containing:
Advance Transfer Appropriation: Diabetes

Fiscal Year 2003

Indian Health Service

Justification of Estimates for Appropriations Committees

To obtain a specific section, refer to the IHS Budget website: http://www.ihs.gov/AdminMngrResources/Budget/index.htm

ACTIVITY/MECHANISMS BUDGET SUMMARY
Department of Health and Human Services
Indian Health Service - 75-0390-0-1-551
DIABETES

Program Authorization:

Program authorized by 111 STAT. 574, 1997 Balanced Budget Act (P.L 105-33) and H.R. 4577, Consolidated Appropriation Act 2001 (P.L. 106-554) and Interior Appropriation IHS National Diabetes Program.

Indian Health Service

Diabetes	2001 Actual	2002 Appropriation	2003 Estimate	Increase Or Decrease
A. Current Law BA	$100,000,000	$100,000,000	$100,000,000	$0
B. Accrued costs	0	0	0	0
C. Proposed Law BA	$100,000,000	$100,000,000	$100,000,000	$0

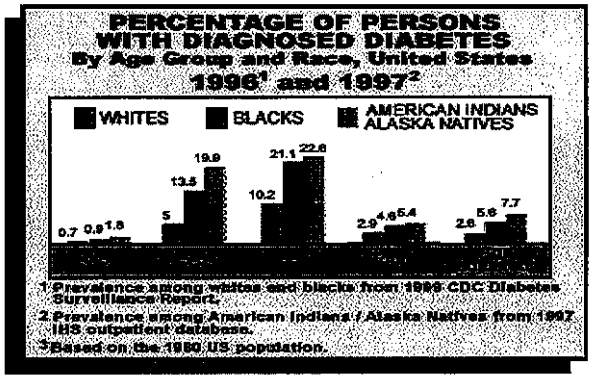
The Balanced Budget Act of 1997 (P.L. 105-33) provides that $30 million per year appropriated to the Children's Health Insurance Program be transferred to IHS for diabetes prevention and treatment. An additional $70,000,000/year was received under the Medicare, Medicaid, and SCHIP Benefits Improvement and Protection Act of 2000 for FY 2001 and FY 2002, and $100,000,000 is available for FY 2003. Total IHS diabetes funding also includes the IHS National Diabetes Program with 12 Area Diabetes Consultants and 19 model diabetes sites ($7.7 million per year) and, starting in FY 1998, an annual $3 million in IHS diabetes grants and $.3 million for a periodontal disease project.

PURPOSE AND METHOD OF OPERATION

Program Mission and Responsibilities

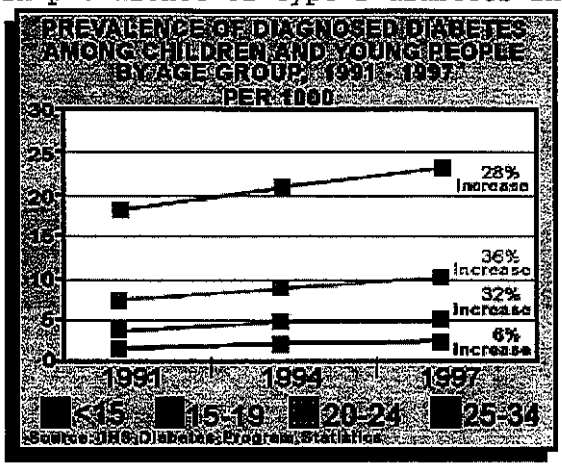
The mission of the IHS National Diabetes Program is to develop, document, and sustain a public health effort to prevent and control diabetes in American Indians and Alaska Natives. The agency promotes collaborative strategies for the prevention of diabetes and its complications in the 12 IHS Service Areas through a network of 19 Model Diabetes Programs and 13 Area Diabetes Consultants. The agency also disseminates current information about all aspects of diabetes surveillance, treatment, education, and prevention.

Diabetes was the most frequently identified health problem in the IHS Area I/T/U budget formulation workshops for FY 2001.



Type 2 diabetes occurs at dramatically higher rates among AI/AN adults who are almost 3 times more likely to have diabetes than the general U.S. population.

A recent alarming trend is the increase in prevalence of type 2 diabetes in young AI/AN. Over a seven-year period, from 1991-1997, the prevalence of diabetes rose 28-36 percent in AI/AN children and adolescents.



Complications of diabetes lead to much higher incidence rates of blindness, vascular insufficiency leading to amputation, and End Stage Renal Disease (ESRD) than in the general U.S. population. Most recent data show that diabetes mortality is 4.3 times higher in the AI/AN population than in the U.S. population. There has been a 24 percent increase in the American Indian age-adjusted death rate from diabetes since 1991-1993. There is clear evidence that for American Indian/Alaska Natives the health disparity related to diabetes is increasing.

The Balanced Budget Act (BBA) of 1997 provided $30 million per year for 5 years through the *Special Diabetes Program for Indians* (SDPI) to provide grants for the prevention and treatment of diabetes to Indian Health Service (IHS), tribal, and urban Indian health programs. The IHS completed a tribal consultation process on the approach to the provision of diabetes services in AI/AN communities. The process included national and regional input from tribal and urban program representatives.

A Tribal Leaders Diabetes Workgroup was established to review the tribal input and make recommendations on the administration and distribution of the BBA funds. Based on the Workgroup recommendations, funds were awarded through non-competitive grants for a five-year project term. The Workgroup recommended that IHS distribute the funding by IHS Area according to a formula based primarily on disease burden (53 percent) and user population with an adjustment to increase funding for very small tribes (42 percent). They also recommended that $1.5 million be set aside for the urban programs who were to be exempt from the distribution formula process. In addition, 5 percent of the overall funds were reserved for improved data collection to enhance the evaluation process. An Area-wide consultation process determined distribution of the grant funds within each Area to local IHS and tribal programs. An evaluation process was created for both the national and Area levels.

There were 286 grants that included 333 separate sites awarded in the first year cycle. Contracts with several tribal organizations were written at the national and regional level to enhance and facilitate evaluation and data collection activities. Ongoing evaluation of the grants, using a mixed methods approach (both qualitative and quantitative methods) has been implemented. Tribal programs determined how their funding was to be used. Sixty-six percent of programs chose to focus on both primary (such as offering exercise and nutrition programs to prevent the incidence of

diabetes) and secondary (managing diabetes to prevent complications such as kidney failure, amputations, heart disease and blindness) diabetes prevention efforts. Thirty-three percent of programs decided to implement tertiary prevention efforts to reduce morbidity and disability in those who have complications from diabetes. And forty-one percent indicated the need for additional planning for their diabetes efforts. Chief Medical Officers, Area Diabetes Consultants and other IHS Area Office Staff were available to assist tribes in choosing promising prevention efforts and in selecting appropriate evaluation measures.

In addition to grants, $1 million of the BBA funds were allocated for the development of a National Diabetes Prevention Center (NDPC) in Gallup, NM. IHS has collaborated with the CDC Division of Diabetes in this effort. The NDPC agreement was awarded to the University of New Mexico (UNM). This past year, UNM redefined the NDPC's area of impact from that of a national perspective to a southwest regional focus. UNM will continue to work primarily with the Zuni Pueblo and Navajo Nation as originally legislated and will expand to work with tribal groups in the southwest. The IHS National Diabetes Program and the CDC Division of Diabetes are working collaboratively to expand the national focus of the NDPC through the dissemination of diabetes technical assistance resources and other diabetes data. The Tribal Leaders Diabetes Committee, established as a result of the BBA funds to advise IHS on diabetes-related issues, will also advise the IHS and CDC on these national expansion efforts.

Tribes have begun to exert a growing influence in the management of diabetes programs. The number of tribally managed programs continues to grow steadily. Eighty-one percent of the *Special Diabetes Program for Indians* grant recipients are tribal programs. To responsibly manage a health program requires data that supports an assessment of the health needs of the population. To meet this need, tribal programs were well represented in the IHS 2000 *Diabetes Care and Outcomes Audit* of AI/AN with diagnosed diabetes and will have the opportunity to participate in the 2001 survey. Data gathered by these surveys provides tribes information from which to make rational decisions regarding their diabetes programs. In FY 2002 the opportunity for the diabetes grant programs to participate in the 2001 audit will expand to include those programs who administer non-clinical, community based diabetes activities. The National Diabetes Program will work with an American Indian Epi-center to develop a method for the non-clinical grant programs to participate in the audit process.

Best Practices/Industry Benchmarks

The IHS Diabetes Program has a long and distinguished history of serving as a benchmark of diabetes clinical and public health excellence. The IHS developed the *IHS Standards of Care for Diabetes* in 1985, prior to those published by the American Diabetes Association in 1987, and are updated every 2 years based on the latest diabetes science. The IHS has been a leader in developing a diabetes care surveillance system, the *Annual Diabetes Care and Outcomes Audit,* carried out voluntarily in Indian health facilities, to track performance on more than 87 indicators to study trends over time. The *Diabetes Care and Outcomes Audit* monitors use of standards and outcomes of diabetes care, including blood sugar and blood pressure control, screening for complications, and preventive health services such as immunizations and smoking history. In the 2000 IHS *Diabetes Care and*

Outcomes Audit, 14,390 charts were reviewed representing care to 82,188 patients at 190 IHS and tribal health facilities in the 12 IHS Areas.

This diabetes care surveillance system has been instrumental in the improvement of diabetes care practices in many Indian health settings. For example, in a special program in Alaska and in northern Minnesota from 1989-93, lower extremity amputation rates were reduced by 50 percent in people with diabetes who received complete foot screening and protective footwear. This same system enabled IHS to measure improvements in blood pressure control in Montana after an intensive intervention in 1993.

Beginning in the late 1970s, the IHS Diabetes Program was a pioneer in developing a public health approach to diabetes. In the early 1980's the program began to publish some of the first national epidemiologic surveillance data regarding the problem of diabetes in AI/AN. The IHS Diabetes Program staff tailored American Diabetes Association education program review criteria to fit the unique needs of Indian communities and disseminated the adapted review criteria nationally. Later in the 1980s and early 1990's, the IHS began to publish in peer-reviewed journals its experience with using the *Annual Diabetes Care and Outcomes Audit* to measure improvements in diabetes care for Indian communities. A 1994 GAO report outlining diabetes care to elderly Americans was compared to 1995 data from IHS. The IHS performed significantly better on all five measures of quality care. In 1998, the IHS Diabetes Program recognized by the Diabetes Quality Improvement Coordinating Committee as one of only two federal agencies who had collected quality improvement data so that it was available for comparison when the Diabetes Quality Improvement Project (DQIP) guidelines were announced. In the January 2001 issue of the medical journal *Diabetes Care* the IHS published an article describing its experience with guidelines and the DQIP measures.

The IHS Diabetes Program has been cited internationally as a model of community involvement and program effectiveness. In 1999 the program was invited to the World Congress on Diabetes Prevention conference to present a description of the Balanced Budget Act of 1997 diabetes grant program. In 2000, the program presented the same information at the 3rd Annual Indigenous People's Conference on Diabetes in New Zealand. As part of its ongoing programmatic activities, the IHS Diabetes Program collaborates with the Centers for Disease Control, the National Institutes of Health, the American Diabetes Association, the National Diabetes Education Program, the American Association of Diabetes Educators, many state Department of Health Diabetes Control Programs, American Indian tribal organizations and tribal colleges and universities.

Findings Influencing the FY 2003 Request

The Balanced Budget Act of 1997 *Special Diabetes Program for Indians* (SDPI) provided IHS $30 million per year for 5 years for the prevention and treatment of diabetes. The amendment to the 1997 Balanced Budget Act SDPI through H.R. 4577, the Consolidated Appropriations Act, 2001 provided additional funding for FY 2001, 2002 and 2003. The 1997 BBA funds have provided "seed money" to 318 new programs to begin, or in some cases significantly enhance, diabetes prevention programs in Indian communities. Many of these programs, the majority of which are tribally managed, are creating innovative, culturally appropriate strategies to address diabetes. The SDPI funds have enhanced diabetes care and education in AI/AN

communities. In FY 2003, some of the funds will be targeted to hire additional trained personnel as well as provide support and technical assistance. The additional funding through the SDPI will enable IHS/tribes/urban Indian health programs (I/T/U) to implement new diabetes activities and/or enhance existing diabetes activities. IHS will be able to continue to refine diabetes data surveillance, monitor diabetes related complications and evaluate activities of the diabetes prevention and treatment efforts.

The Consolidated Appropriations Act of 2001 provides additional new diabetes funding, $70 million for year 2001, $70 million in year 2002 and $100 million in Year 2003. Beginning in January 2001 IHS has worked collaboratively with the Tribal Leaders Diabetes Committee (TLDC) to conduct nationwide tribal consultation on this new diabetes funding. Consultation included tribal leadership in each IHS region and representatives of the urban Indian health programs. In FY 2001, $63 million will be distributed among eligible tribal grantees utilizing a formula approved by the IHS Director based on recommendations from the TLDC (disease burden consisting of mortality and prevalence, 57.5 percent; user population, 30 percent; and tribal size adjustment, 12.5 percent). $7 million will be divided between urban health programs and administrative support. The new diabetes funding is being administered as a non-competitive supplemental grant program. Additional tribal consultation will provide input to IHS on the formula for distribution for FY 2002 and FY 2003. The new diabetes funding is being used to supplement the existing grants (through the Grants for Special Diabetes Program for Indians, 1997 BBA) for diabetes community-based clinical and non-clinical services for AI/AN.

In anticipation of the increased amount of funding to grantees, the FY 2001 Application Kit for Supplemental Grant Funds included

- a Community Assessment Tool to assist grantees to determine how diabetes care and/or prevention is being addressed in their community, and
- 14 suggested diabetes best practices based on experiences of other Indian health diabetes programs as well as on findings from diabetes scientific research and outcomes studies.

Grantees were given the option to strengthen clinical diabetes and complications prevention programs and/or to develop and strengthen primary diabetes prevention programs. Supplemental Grant awards will be awarded to 307 IHS/Tribal and 35 urban Indian program. The IHS National Diabetes Program will strengthen the IHS diabetes infrastructure at the Headquarters and Area office levels to maintain and improve diabetes surveillance, technical assistance, provider networks, clinical monitoring and grant evaluation activities.

Support for the Area Diabetes Consultants, who serve a crucial role in coordinating these functions at the Area level, will be strengthened. In order to maximize communication with grantees, a series of regional meetings will provide the opportunity to meet "face-to-face" with grantee staff and tribal leaders to provide grants and diabetes related information. Additional support specifically for grants monitoring and technical assistance will be strengthened through the National Diabetes Program office.

The next challenge for IHS on a national level will be to disseminate the new ideas learned in these grant site settings to other tribal communities for adaptation and implementation. A compendium of grant program descriptions is being compiled for dissemination nationwide. In addition, an in-depth analysis of grant program activities will provide a compilation of "best practices" developed through these community and urban Indian health programs.

ACCOMPLISHMENTS

Results of the 2000 IHS-wide *IHS Diabetes Care and Outcomes Audit* to assess diabetes care and education for over 82,000 diabetes patients completed in 2001 revealed an important finding. Data comparisons with 1994-97 results showed a statistically significant improvement trend in blood sugar control among the AI/AN with diagnosed diabetes. This encouraging trend has occurred in spite of the inability of many IHS and tribal facilities to purchase newer diabetes medications and equipment. The IHS National Diabetes Program attributes this trend to the extensive commitment that IHS and local communities have made to improve diabetes control. Blood sugar control has been definitively shown in large clinical trials to reduce the complications of diabetes over time and to save money. The impact of the new diabetes funding on continuing to improve the clinical and programmatic capabilities of the diabetes grant programs is not measurable at this time. It is anticipated that over time continued improvements will occur.

Publications documenting our ability to improve care with low tech, low cost approaches have been numerous. Unfortunately, the costs of providing diabetes care are prohibitive. Estimates from managed care organizations suggest that the average cost of diabetes care is $5,000-$9,000 per patient per year, much of this a result of the costs of pharmaceuticals. Yet, the IHS per capita is $1,578. Thus, the limited resources for diabetes care in the Indian health system have mostly been devoted to the clinical care of diabetes and prevention of its complications, rather than to less well scientifically proven methods for primary prevention of diabetes in those without the disease. The recent announcement from the Type 2 Diabetes Prevention study that lifestyle change provided a significant deterrent to the development of type 2 diabetes offers a challenging opportunity to those diabetes grant programs that provide diabetes prevention activities. Despite these advances, AI/ANs continue to have substantially higher rates of diabetes and its complications than the U.S. population at large.

Specific accomplishments include:

- The IHS National Diabetes Program continues to work closely on diabetes-related issues with tribal leaders through the Tribal Leaders Diabetes Committee (TLDC). This committee was established by Dr Trujillo to advise the agency on an ongoing basis. The TLDC worked collaboratively with IHS to conduct national and regional tribal consultation on the distribution of the FY 2001 $70 million in new diabetes funding.

- The IHS National Diabetes Program staff play significant roles on numerous national diabetes activities:
  - ✓ The Director serves as a Steering Committee member on the National Diabetes Education Program (NDEP); as a member of the Translational Advisory Committee of the CDC Division of Diabetes; as an ad hoc member of the Congressionally-mandated Diabetes Research Working

Group of the NIDDK/NIH; as a member of the Federal Diabetes Interagency Coordinating Committee; on the President's Quality Interagency Coordinating Committee - Diabetes Subcommittee; and as a member of the President's Committee on Health Disparities - Diabetes Committee.

- ✓ Other staff serve on the National Board of Directors of the American Diabetes Association, the Task Force to Review the National Diabetes Education Standards for Diabetes Self-Management and the NDEP American Indian sub-committee.

- The IHS National Diabetes Program initiated an Indian health task force to revise and develop a framework for integrating Diabetes Education Standards for AI/AN communities. The task force has developed a process for achieving formal recognition of quality programs in preparation for CMS, formerly known as HCFA, reimbursement of diabetes education. The IHS has applied to CMS, to become a deeming entity for Indian health education programs.

- The IHS National Diabetes Program and the CDC Division of Diabetes collaborate closely. The IHS Diabetes Program prevalence and complications surveillance system have been automated through the assignment of a CDC Epidemiologist to the program. The prevalence data have been disseminated to the Tribal Leaders Diabetes Committee, Area Directors, Area Diabetes Consultants, and others. The data are now available by region on our website. In addition, IHS and CDC Division of Translation are working together on the national expansion efforts of the National Diabetes Prevention Center currently housed in Gallup, NM.

- A Workgroup has been established with CDC, IHS, the American Academy of Pediatrics and the American Diabetes Association to address the growing concern about type 2-diabetes in Native American children. IHS staff is leading the effort with requests for screening protocols, standards of care and treatment recommendations from these expert groups. Work has begun to develop diabetes education resources for these young patients who have type 2 diabetes and their families.

- The IHS established an obesity prevention initiative in 1998 to address the increasing trend of obesity in children ages 3-5 years of age. In partnership with other federal agencies, states and Tribes, the IHS Diabetes Program developed a comprehensive plan for a four-year initiative. Five pilot sites have recently been selected to implement obesity prevention interventions in tribal Head Start programs and communities.

- The IHS National Diabetes Program (NDP) partnered with the National Indian Council on Aging (NICOA) to develop a pilot project to automate diabetes clinical data at the local and national levels. At this time eight sites are fully functional and will continue to provide the NDP with process information on accessing diabetes data through the automated process with the eventual goal of integrating with the IHS RPMS.

- The IHS National Diabetes Program collaborated with Macro International, INC, a consultant firm specializing in mixed methods evaluation, to

develop an evaluation strategy for the SDPI grants program in 1999. These data served as a major portion of the analysis in the Year 2000 Interim Report to Congress. Data are currently being collected for a revised year 2001 evaluation report. In addition, Macro International, INC is working to develop an evaluative process that will assess the IHS Model Diabetes Programs that had their beginnings in 1979. The Indian Health Care Improvement Act has called for an evaluation of the impact of these programs.

PERFORMANCE MEASURES

Over a short period of time, the National Diabetes Program expanded from a $7.7 million program comprised of a national office, 12 Area Diabetes programs and 19 model diabetes programs into a $100 million program with over 300 additional I/T/U diabetes grant programs in the field. The initial performance measures developed over 5 years ago realistically apply to less than 10 percent of activities for this $100 million program. There is a critical need to accurately measure the performance of the new diabetes grant programs. Utilizing the current performance measures, the National Diabetes Program will begin to identify subset measures, baseline and trend data, and other methods for reporting diabetes grant prevention program activities.

The performance measures associated with this budget request are as follows:

Indicator 1: During FY 2003, continue tracking (i.e., data collection and analyses) Area age-specific diabetes prevalence rates to identify trends in the age-specific prevalence of diabetes (as a surrogate marker for diabetes incidence) for the AI/AN population.

Indicator 2: During FY 2003, maintain the FY 2002 performance level for glycemic control in the proportion of I/T/U clients with diagnosed diabetes.

Indicator 3: During FY 2003, maintain the FY 2002 performance level for blood pressure control in the proportion of I/T/U clients with diagnosed diabetes who have achieved blood pressure control standards.

Indicator 4: During FY 2003, maintain the FY 2002 performance level for the proportion of I/T/U clients with diagnosed diabetes assessed for dyslipidemia (i.e., LDL cholesterol).

Indicator 5: During FY 2003, maintain the proportion of I/T/U clients with diagnosed diabetes assessed for nephropathy.

Funding for the *Special Diabetes Program for Indians* during the last five years has been as follows:

Year	Funding
1998	$30,000,000
1999	$30,000,000
2000	$30,000,000
2001	$100,000,000
2002	$100,000,000